

## Self Advocacy:

### The Key for **EVERYONE'S** Success



## PRESENTERS



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*This is MY Life* Peer Advocate Trainer  
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## DDD & Centers for Independent Living (CIL) Partnership Program


### ***This is MY Life Program***

Trainings on Self Advocacy and  
Self Determination skills for people age  
16 and over who use DDD services.

- Partnership with Maricopa and Pima County CILs since 1997
- Individual or group trainings
- No service dollars used



# Today's Learning Goals

1. Where and why self advocacy developed- history of Centers for Independent Living and disability rights.
  2. People First language.
  3. Value of self advocacy skills in life.
  4. Tools & Methods for teaching self advocacy.
  5. Resources to help you teach self advocacy.
- 



Ability360 is a nonprofit that offers and promotes programs designed to empower people with disabilities to take personal responsibility so they may achieve or continue independent lifestyles within the community.



# Centers for Independent Living

The term “center for independent living” means a:

- consumer-controlled,
- community-based,
- cross-disability,
- nonresidential,
- private nonprofit agency.

There are over 400 Centers for Independent Living in the United States.

## Arizona

*Tuba City - ASSIST!*

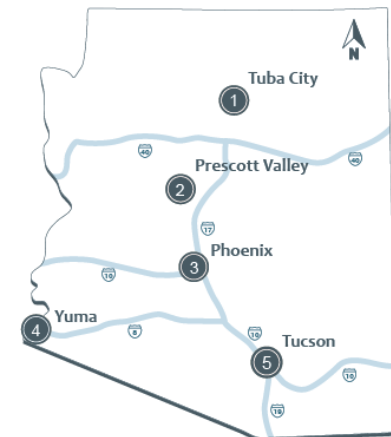
*Prescott Valley – New Horizons*

***Phoenix - Ability360***

*Yuma - SMILE*

*Tucson - DIRECT*

ARIZONA CIL NETWORK



# Centers for Independent Living

## Five Core Services

- **Information and Referral**
- **Independent Living Skills Instruction**
- **Peer Support/Peer Mentoring**
- **Advocacy** - Individual and Systems
- **Transition**- Assisting people with moving from nursing homes to less restrictive living arrangements; youth to adulthood; and rehabilitation settings to the community.

# Ability360 Programs

- Advocacy / ADA Services
- Independent Living Skills Instruction
- Information & Referral
- Peer Support
- Ability360 Employment Services
- Early Intervention to People Newly Disabled
- Empowering Youth in Transition
- Employment and Work Incentives Consulting for Social Security beneficiaries
- Home Modification
- Home Care Services
- Living Well with a Disability
- Nursing Home transition to Community Living
- ***This is MY Life: Self Advocacy and Self Determination Skill Training***
- Socialization Through Recreation
- Ability360 Sports and Fitness Center
- Theatre360

Most Services  
Free

# Self Advocacy is a Civil Rights Movement

## *Civil Rights*

The history of independent living centers and self advocacy is closely tied to the civil rights struggles of the 1950s and 1960s among African Americans.



# History of Self Advocacy

You need to understand the history in order to teach the importance of it

***People with disabilities were inspired to advocate!***



The Great Fight for Disability Rights

"The Great Fight for Disability Rights" trailer with subtitles

# History of Independent Living & Self Advocacy

***People with disabilities  
were inspired to advocate!***

## ***Basic issues:***

- Disgraceful treatment based on prejudice and negative stereotypes
- Discrimination and segregation in housing, education, transportation, and employment
- Lack of opportunities for people with disabilities to participate in society



# Self Advocates using Self Determination is a National Movement



The self-advocacy movement is basically about people with disabilities [speaking up for themselves](#).

It means that a person with a disability might need to ask for the support of others, but they are still in control of their own services and how they are directed.



# Success in Advocacy Efforts



Medicaid Expansion Passed

AZ statute language from handicapped to persons with disabilities passed



Group home residents have 30% of their SSI benefits restored



Spread the Word to End the Word Campaign and pledge, every 1<sup>st</sup> Wed in March.

(Society awareness campaign to stop hurtful R-word language)

Language affects attitude.  
Attitudes affect actions.

Make your pledge to use respectful people first language at [R-word.org](http://R-word.org)

**SPREAD THE WORD  
TO END THE WORD**





# People First Language

## What is People First Language?

- Seeing beyond the disability diagnosis.
- A disability is defined as a body function that operates differently. It's not the person!

## Why is it important?

- It focuses on abilities, what I can do! (not on what I can't do)
- I am a person first, not my disability label.



**# I'M A PERSON**  
NOT A DISABILITY

# Importance of People First Language

- Speak about my needs. (Not about my behaviors or my problems)
- Treat everyone equal. (We are all human)
- Wait for the person to ask for help. (Maybe I CAN do it!)
- Let the person speak in their own words.
- Talk directly to the person first with the disability, not staff or parent.

**“Our words affect the world”**

~Teresa Moore, National Self Advocate



# Teaching Self Advocacy

## 1. Components of Self Advocacy

- a) Know Yourself
- b) Know Your Rights
- c) Effective Communication

## 2. Creative Tools

## 3. “The How’s” to teach it



# Resource Video

## Self Advocacy Teaching

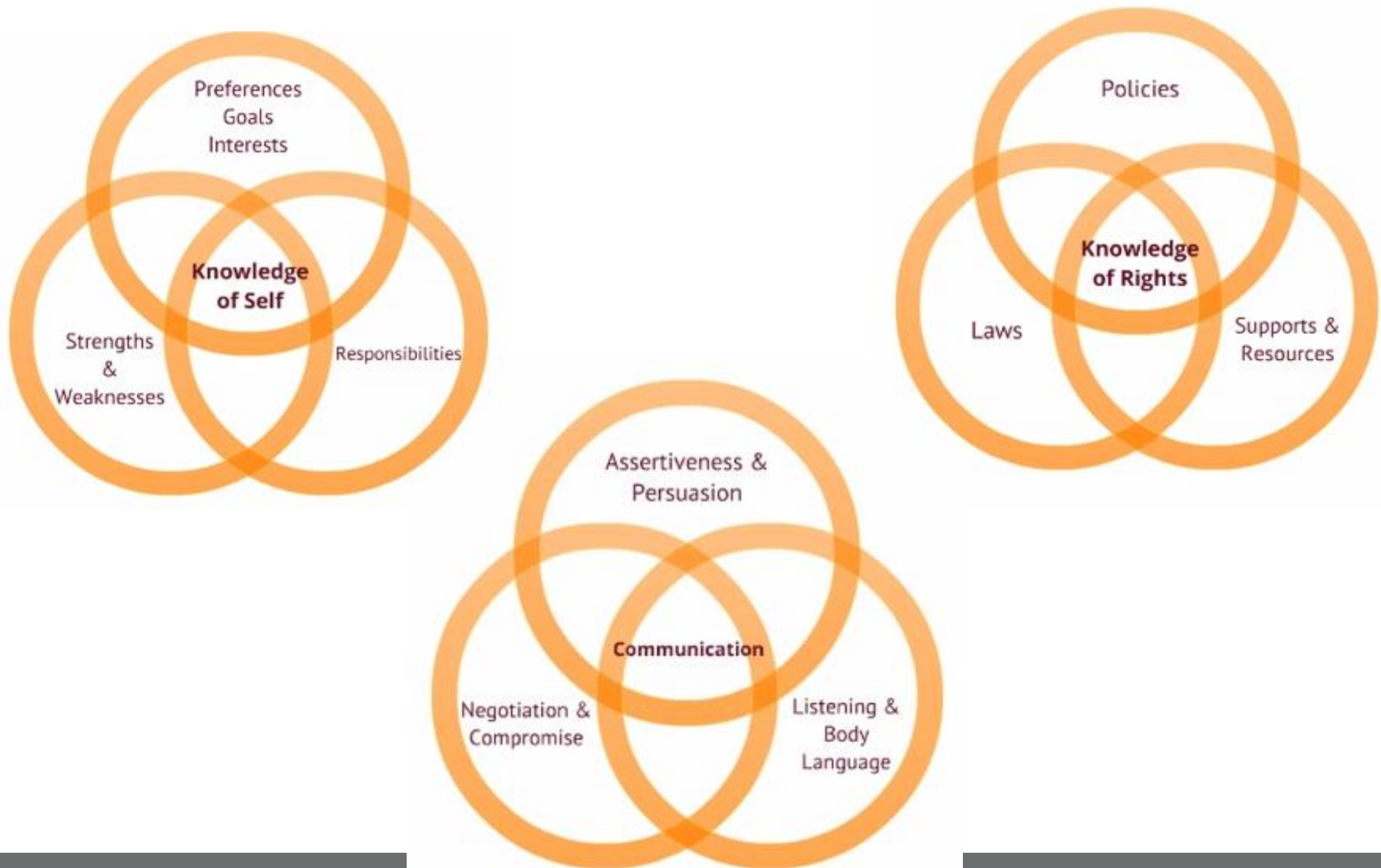
Research indicates the predictor for success (for people with learning disabilities) is having the essential skill of SELF ADVOCACY!



StrategyTube - Self-Advocacy & Students with Learning Disabilities

<https://www.youtube.com/watch?v=Ev6BYogoKEo>

# 3 Main Components in Self Advocacy



# Self Advocacy Main Components

## #1- Self Awareness is the Critical Foundation

Personal and  
Academic  
Self Awareness



## Activity

# Know Yourself!

You know yourself best- This makes it easier to self advocate



- Your Abilities  
(Things that you can do)
- Your Talents  
(Things that you can do that not everyone else can do)
- Your Likes
- Your Dislikes
- Your Struggles  
(Things are hard for you or may need help with)

# Activity: Know Yourself!

This makes you a stronger self advocate

## Know About My Disability-

Know and understand your disability. Be able to explain your disability, how it affects learning, and the accommodations you might need personally, academically, and in employment.

- If you don't know this very important information—

**ASK!**



## Activity:

# Know Yourself! Accommodations

Tools that make it easier for people with disabilities to do the same things others do.

- A reader for you
- Wheelchair access
- Communication board
- Computer or adaptive software
- Books on tape
- Need more time to do things
- Large print
- Transportation

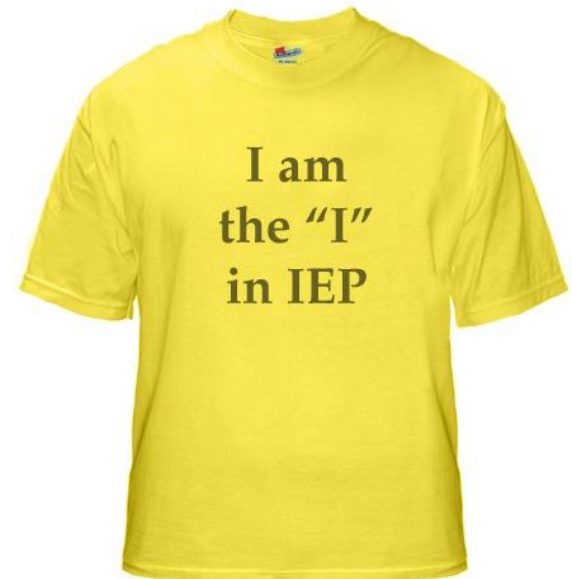
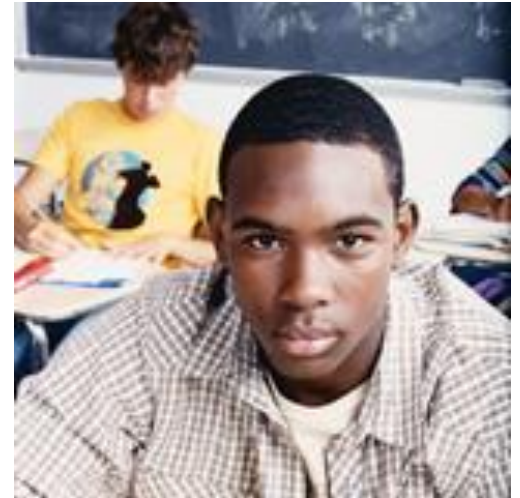


**Know Yourself!**

# **Encourage Student led IEP/ISP**

## **Student Involvement in the IEP/ISP:**

- Builds self advocacy skills and self esteem
- Gives control over their education
- Builds important social and conversational skills
- Teaches the processes of decision-making, goal setting and achievement



# **Activity** Tools to Self Advocacy ~ **Responsibilities**

**Response Ability-** What's MINE to do and what's YOURS to do?

**Recognize if you are having problems at school, work, home** - ASK for help. YOU are in charge of your SUCCESS. (*Possible supports: job coach, independent living skills, campus disability services*)

**Identify yourself as the decision maker and problem solver-** Issues that your parents or teachers handled are directed to you now. If you don't know, ASK trusted person for help, and YOU make the final choice. (*Possible supports: problem solving skills development*)

**Take charge of your transportation-** Needed to get to your job, grocery store, doctors, college - YOU arrange it! (*Possible supports: Bus training, dial-a-ride, pay friend to drive, maybe Health insurance or vocational rehabilitation will pay*)

# Activity Tools to Self Advocacy ~ Responsibilities

**Response Ability-** What's MINE to do and what's YOURS to do?

**Technology, Medical Equipment, Accommodations Oh My!** Know your health care insurance coverage, ADA rights and seek what services are in the community. (*Possible supports: campus disability service, Centers for Independent Living, Vocational Rehabilitation, AZTAP, Disability agencies*)

**Staying healthy:** Change from pediatric to adult healthcare system; arranging medical appointments; Practice decision making now at doctors visits – start early! (*Possible supports: Health care literacy - learn health plan name; medications, refills and usages and budgeting for co-pays and Rx; medical equipment services; therapies; recognize symptoms of illness; medical power of attorney.*)

*Self advocate for who you trust to support you!*

# Self Advocacy Main Components

## #2 KNOW YOUR RIGHTS

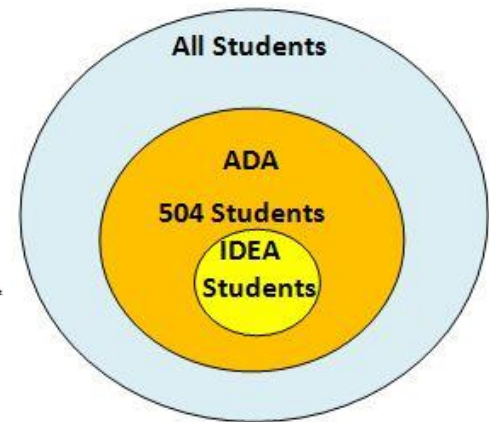
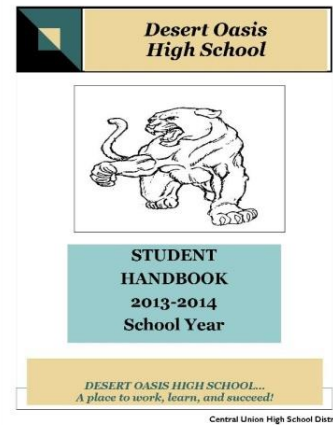


Individual,  
Student, and  
Society

# Self Advocacy Main Components- Rights

## Knowledge of Rights

- Personal
- Community
- Human Service
- Consumer
- Educational



## Steps to Advocate for Change

- How systems work
- Steps to address issues



## Knowledge of Resources

Videos



Training Materials



Blogs



Webinars



# Resource Video- Rights



Know your Rights: A Guide for Self-Advocates

[https://www.youtube.com/watch?v=NRA5rTuK\\_es](https://www.youtube.com/watch?v=NRA5rTuK_es)

# Self Advocacy Main Components

## #3 EFFECTIVE COMMUNICATION



# Activity Communication: How do I do it?

**WHAT IF:** I am too nervous.. I am too shy... I don't use words to speak? People have trouble understanding me...



Verbal

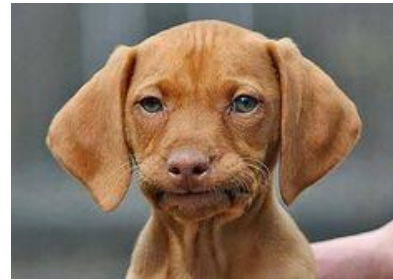
Facial  
expressions

no

yes



Sign language or  
Gestures

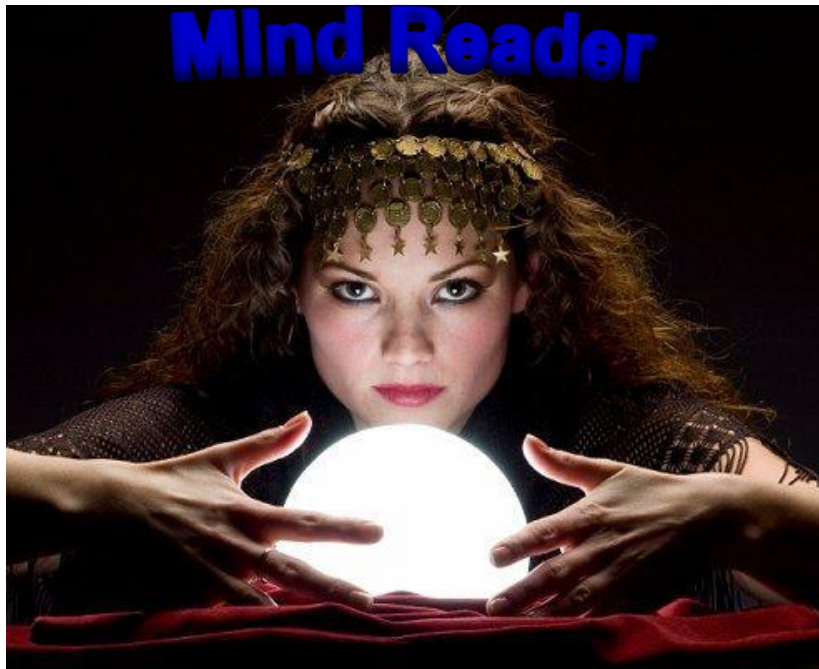


Texting

Eye contact



**Activity** My Parents, Guardian, Teachers, Staff,  
Friends know what I want.  
I don't have to speak up.



**YES You Do!**

**If you don't speak up, they  
have to do their best to guess.**

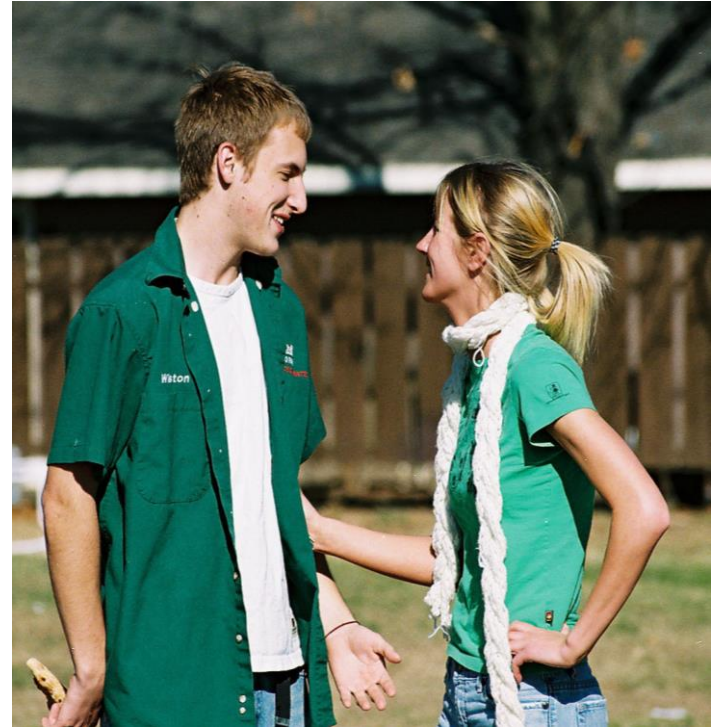


# Activity How do I Speak UP?

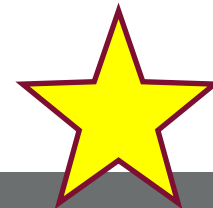
## Which one works?



Demand or Yell for what you want?



ASK nicely and respectfully



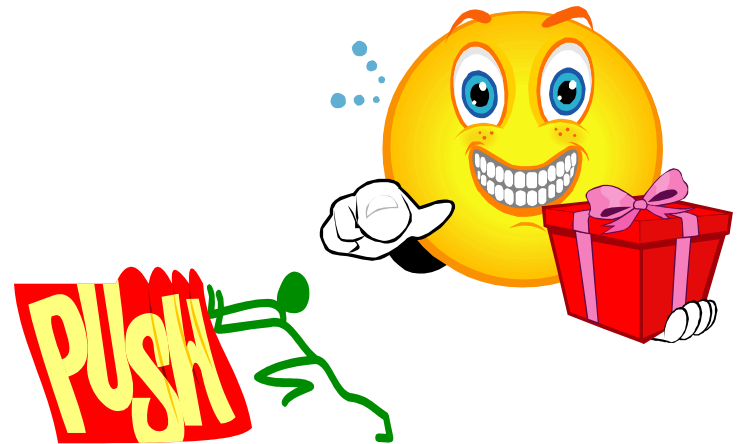
# Teaching Self Advocacy

## Communication Styles Role Playing

Activity  
**ABILITY360**

### Difficult:

- Conditional Communications
- Pushy or Tricky Communications
- Angered Communications



**Non Verbal:** (does not stop you from participating in self advocacy or in the community)

Body Language, posture, assistive technology, silence, eye contact, and gestures

Negotiating, Compromise and Persuasion

Respectfully & Calmly:

ASK Questions! ASK Why! Say No Thank You.



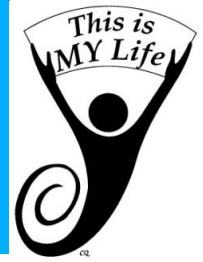
# Activity Self Advocates Told Us Why Self Advocacy is Important



- "I stand up for myself."
- "I believe in myself."
- "I am in charge of my life."
- "I know my voice matters."
- "I say what I think."



# Self Advocacy Basic Teaching Topics



*SELF-ADVOCACY IS ASKING FOR THE THINGS YOU WANT AND TAKING ACTION TO REACH YOUR GOALS.*

- **What is it? Why it's important?**
- It is for EVERYONE- verbal or nonverbal, all kids and adults
- **You decide to be a self advocate or not**
- People are not mind readers
- **How to do it- voice tone, words used, gestures (Model it)**
- Who to self advocate to- Guardian, parents, teachers, medical, community, peers
- **Where to Self advocate- every day life, IEP and ISPs, for accommodations**
- What happens when I don't self advocate

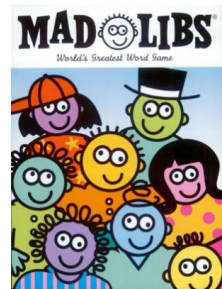
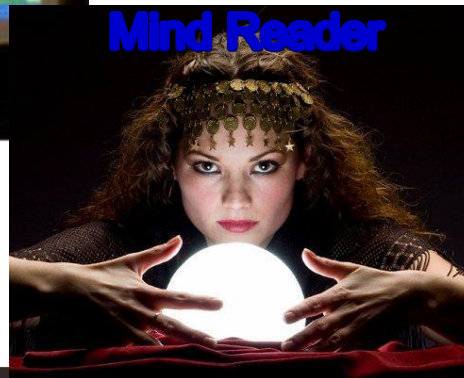
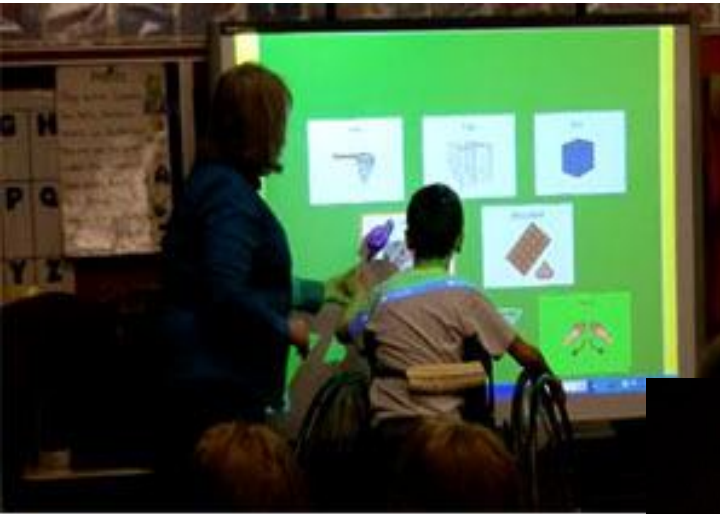


# Self Advocacy Basic Teaching Topics

- **Do I only self advocate for the things I like or can I for things I don't like too?**
- Self advocate for little and big things
- **Is it hard to speak up? Afraid hurt someone feeling or they'll be mad at you?**
- Will I always get what I self advocate for?
- **Things that can get in your way/barriers: having patience to get what you want**
- Problem solving and where to go for help: YOU choose who you trust to help you
- **Advanced self advocacy- community, systems and advocating for others**
- Celebrate success



# Creative Tools and Variety



# **Creative:** You are born a Self-Advocate!



## **YES!**

**EVERYONE** is a  
self advocate!

With and even without  
verbal words.

# Creative: Self-Advocacy IS: Speaking Up about BIG and small choices in your life



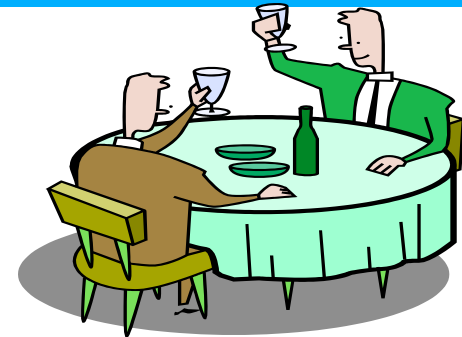
I choose what I wear



Deposit \$\$ or pay my own bills



At work



Server speaks directly to me



At School or Program and IEP or ISPs



I know my medications -how many, what color & what they are for



Privacy-  
People knock before entering



How to cook



People need to talk and listen to ME

# Group Activity

Labels or Diagnosis's should only be used to get the services you need.

Activity: Write down on a blank label to give to the person:

- Let's talk about what really counts about you.
- Tell us something that makes you awesome or have your friend tell us what makes you awesome.
  - Smart
  - Always helpful
  - Good friend, son, daughter...



**YOU ARE MUCH MORE THAN YOUR DISABILITY LABEL!!**

# Using Videos for Fun & Learning

Self-Advocacy: Find the Captain in You!



# Self Advocacy Videos

**Self Advocates Say What  
Self Advocacy Means to Them**



**I Define Who I Am, Not Others**



I define me!

Sharing creative activities  
you have used



**Shout Out  
Time!!**

# How We Teach Self Advocacy



1. **Creative Learning Process-** Adapting materials to specific people's learning styles. Try different approaches- it's all trial and error. It is unique to the individual.
2. **Review** information
  - **Rephrase** information several different ways/times
  - **Recognize** common items of pictures/icons for recall and reading barriers
  - **Role play** using examples and humor to retain information
  - **Relate** it to their world, things they enjoy
  - **Recall-** improved for some with repeating
- **3. Peer Led Training-** The instant personal connection with someone who looks like me and has a story to share similar to mine. Provides a pathway to the future.

# How We Teach Self Advocacy

- **Meet them where they are at-** they may just listen and not want to participate, and that's ok.
- **Pursue a connection with each person-** Eye contact, name recognition, body language, and gestures.
- **Encourage to try-** everyone is fair game-whether they speak or not. Trying is the 1<sup>st</sup> step to being a leader!
- **Focus on meaning and concepts-** don't get hung up on vocabulary. Some will remember words and some ideas.
- **Match keywords to graphics**
- **Shoot for understanding and a placement in their memory-** by sound, image, activity and lots of examples.

# The How of Teaching Self Advocacy

- **Simplify it-** smaller steps, less written words and more graphics
- **Model it-** I'll do it first; now we will all do it together; now you do it- try it on your own
- **Role Play** – act it out using real life examples. Fun but real!
- **Summarize** at end- to help put information into long term memory.

## **Repeat, Repeat, Repeat**

- **Your building self advocacy skills over time.**
- **Be patient with the process-** work with the person's disability.

# More How's - Include in Every Class!

## Skill Retention

- **Welcoming-** get each to share something about themselves. Ask a question everyone can answer.
- **Intro Review: What is a self advocate?** – How did you speak up this week? Memory refreshers, pictures of definitions, etc...
- **Self assessment-**
  - How did you self advocate this past week? (Celebrate!)
  - Failures are as important as successes (Sharing strategies)
- **Review** – Repeat the past concepts learned from previous training before new topic.
- **Peer/Student leadership** – Give opportunities for them to teach; like the review.

# Value of Using Peers



- Students have instant connection to peer trainer, enjoying the change and thinking it's fun.
- Confidence booster: If they can learn it - maybe I can too?
- Provides personal stories of success and failures.
- Provides honest answers on how much effort it takes to do it
- Peers can decode answers from students to help further the understanding and tweak learning and curriculum.
- Helps teacher deliver difficult topics:  
Barriers, disability etiquette, People First language, overcoming failures, managing staff and family issues

## Remember Being a Self-advocate means

I don't have to do it all myself.  
I can ask the people I trust to  
help me.



Self advocating doesn't mean  
I will get everything I ask for...  
BUT if I don't ask, I will never  
know if I could get it!

# Supporting Self Advocacy- How to Help: Parents and Teachers are Key!

- **Create Opportunities:** to practice being a self advocate. Provide key information about their daily life and only give assistance when asked.
- **Role play situations-** that make them nervous or when they hear NO (Discuss disappointments that may occur and how this happens to us all).
- **Allow them to be a self advocate and take risks-** you can always be nearby
- **Encourage positive self attitudes and self awareness of abilities and struggles-** This is a natural life skill all adults learn at home, school, and in the community. Even though people may not speak, they are listening to everything. Fake support can be felt and hinders success.
- **Self-advocacy skills improve over time.** Students will develop their own strengths from challenges and learn how to express their needs, wants, and rights.

# Resources

## Videos

- The Great Fight for Disability Rights: <https://www.youtube.com/watch?v=LG2KryP89Eo>
  - <http://storylinemotionpictures.com/purchase-a-dvd/> Purchase link
- Students with Learning Disabilities Succeed Beyond School: (Teach Method Self Advocacy) <https://www.youtube.com/watch?v=Ev6BYogoKEo>
- Know your Rights- A guide for self advocates: [https://www.youtube.com/watch?v=NRA5rTuK\\_es](https://www.youtube.com/watch?v=NRA5rTuK_es)
- Self Advocacy- Find the Captain in You: <https://www.youtube.com/watch?v=NUQDozx7aug>
- What is Self-Advocacy? [https://www.youtube.com/watch?v=sOX3LWUD2\\_g](https://www.youtube.com/watch?v=sOX3LWUD2_g)
- I Define Me!: <https://www.youtube.com/watch?v=opgUMJTXY>
- Life worth Living: <https://www.youtube.com/watch?v=RIXm9NJDacM>
- Self Advocates Online (Personal Stories): <http://www.selfadvocacyonline.org/stories/?story=OIUWtaU8ZXM>
- Ten Steps To Effective Self-Advocacy: <https://www.youtube.com/watch?v=K6n3uFdXo2Y>

# Resources

## Websites

- Ability360: <http://ability360.org/ability360-at-a-glance#>
- Advocating Change Together (ACT) Toolkits: [www.selfadvocacy.org](http://www.selfadvocacy.org)
- Self Advocates Becoming Empowered (SABE) [www.sabeusa.org](http://www.sabeusa.org)
- Disability is Natural [www.disabilityisnatural.com](http://www.disabilityisnatural.com)
- Full Life Ahead Workbook: <http://www.fulllifeahead.org/workbook-english-2/>
- Raising Special Kids: <http://www.raisingpecialkids.org/>
- Independent Living Research Utilization: <http://www.ilru.org/home>
- Disability Rights Education and Defense Fund- <http://www.dredf.org>
- Arizona Developmental Disabilities Planning Council: <https://addpc.az.gov/about>
- Legal Options Manual (Guardianship) <https://www.azdisabilitylaw.org/wp-content/uploads/2015/04/LegalOptionsManual2012-Eng.pdf>
- Arizona Center for Disability Law: <https://www.azdisabilitylaw.org/guides/>
- Disability Benefits 101: [www.az.db101.org](http://www.az.db101.org)
- Southwest Institute for Families and Children (SWI): <http://swifamilies.org/>
- AZ Technology Access Program: AZTAP: <http://aztap.org>
- Person-Centered Planning (PCP): <http://pcp.sonoranucedd.fcm.arizona.edu/node?destination=node>

# THIS IS MY LIFE

Self-Advocacy Making Choices Directing Your Life



Individual or group trainings for people  
16 and over using DDD services

## ABILITY360

ADVOCACY | INDEPENDENCE | EQUALITY

# Resource

## For Individuals in DDD System 16 yrs+

Lynn Black, MSW-LCSW  
This is MY Life Program Manager  
602-443-0729  
lynnb@ability360.org

<http://ability360.org/this-is-my-life>



TIML is funded by Arizona Department  
of Economic Security's DDD contract.  
These trainings are copyright protected.

No DDD service dollars used.



### LEARN SELF-ADVOCACY:

- Say what you need and want
- Feel better about yourself
- Work towards something you want
- Know how to solve problems
- Have better relationships
- Use your words respectfully
- Improve communication with friends, family, staff, guardians, employers and doctors

### LEARN SELF-DETERMINATION:

(Make Choices)

- Understand DDD services and how to make changes
- Learn about other community services
- Learn your rights and responsibilities
- Speak up at your ISP (Big Meeting) to get what you want and need
- Make choices in your life, like what to wear and where you live, work and play

THANK YOU & Any Questions?



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